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Title

Palliative care provision for patients with a hematological malignancy: Can we do more?

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Conflicts of Interest:

The authors declare that they have no conflicts of interest.

There have been significant advancements in the care of patients with a hematological malignancy over the past three or more decades¹. Despite this, there still exists a significant mortality risk in curative treatment and many patients with a hematological malignancy will die from their disease¹. A growing body of research indicates patients with a hematological malignancy do not receive best practice palliative and end-of-life care². Shortfalls in care include poor referral patterns to specialist palliative care services, lack of honest discussions regarding death and dying, inadequate spiritual care for patients and families, patients frequently dying in the acute care setting and high levels of patient and family distress². There have been a number of efforts in the United Kingdom, United States of America, Sweden, and Australia demonstrating palliative and hematology care can co-exist, exemplified through clinical case studies and innovative models of care². However, deficits in the provision of palliative care for patients with a hematological malignancy persist as evident in the international literature². Addressing this issue requires research exploring new aspects of a complex scenario; here we suggest priority areas of research.

The Patient’s Voice

While the experience of the bereaved caregiver and opinions of health care professionals have been explored², to the best of our knowledge the patient’s voice is missing in the literature. Published case studies demonstrate successful integration of palliative care when patients are provided with open, honest information and treatment options^{3, 4}. It is acknowledged that research exploring the patient’s perspective in palliative care is difficult for ethical and practical reasons. However, patients with a hematology malignancy are often functionally well and physically able to participate in research despite having advanced disease, providing the opportunity for valuable insights to be shared even late in their illness trajectory. Revealing the

patient's voice is the next step forward in addressing the problem of inadequate palliative care provision for patients with a hematological malignancy.

The Uniqueness of Hematology

The unique nature and disease trajectory of patients with a hematological malignancy must be considered as these patients are much more likely to have fluctuating levels of health and to deteriorate rapidly to a terminal event than their solid tumor counterparts². It is argued that current models of specialist palliative care services and end-of-life care facilities are geared towards patients with solid tumors who experience a slower steady decline^{1, 5}. Treatment that is viewed as 'symptom management' by hematologists is often considered 'active treatment' by palliative care physicians and is not facilitated in palliative care units⁵. In light of these limitations, formal study of how well specialist palliative care services can care for patients with a hematological malignancy is needed.

Contribution of cancer nurses

In response to increasingly complex health care systems, nursing roles are expanding and becoming more valuable in meeting the needs of specialized patient groups⁶. Advanced practice nursing roles such as the role of nurse practitioner have great promise in improving holistic care and streamlining integration of palliative care, potentially resulting in improvements in symptoms, levels of emotional distress and quality of life⁶. However, much attention has focused on nursing competence in performing 'medical tasks' such as bone marrow aspirates, insertion of central lines and managing transfusions. The holistic model of nursing must not be undervalued or underutilized in advanced nursing roles. A high level of evidence supporting the effectiveness of these roles and models of care will be required.

Cancer nurses can do more to improve palliative and end-of-life care provision for patients with a hematological malignancy. First and foremost, we need to help the patient's voices be heard and understand their perspectives, perceptions and understandings. This is certainly an exciting time for cancer nurses, as we have significant potential to improve the complex and unmet needs of patients with a hematological malignancy, and help tailor palliative care to meet their specific needs.

(Author names withheld as required)

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